Public and Patient Involvement and Engagement (PPIE) must lead the way in data partnerships:

Flatiron Health UK's Why, What and How

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Why

In an age where data is often touted as the new oil, managing personal health data has become one of the most pressing ethical questions. As public-private partnerships in data use grow, one principle must guide these relationships above all others: meaningful Public and Patient Involvement and Engagement (PPIE) – not just a moral imperative, but a strategic one, embraced by Flatiron Health UK.

Flatiron Health UK works with NHS Hospitals, patients, charity organisations and researchers in both academia and industry to expand the impact of real-world evidence in cancer. The amount of cancer-related data we now have is re-shaping conversations beyond traditional indicators like survival rates, morbidity and demographics.

It's exciting, but also daunting. Often, it feels like we are building the plane whilst flying it. We're navigating a complex landscape of clinical uncertainties, for example: siloed data, limited public understanding, fragile tech infrastructure.

Data is powerful, but also easily misused. We are data-rich, yet often information poor.

But if we ask the right questions, data can be transformative. Should we stop focusing solely on cure and instead prioritise extending life? Should we be using data to report on what matters to patients and their caregivers? Can data help redefine outcomes?

What has Flatiron Health UK done to create a new social contract for patient data?

The future of data-driven innovation depends on a new social contract – one that sees people as partners, not just data sources. PPIE isn't a barrier to progress; it's the foundation of legitimate, responsible and impactful progress.

Flatiron Health UK demonstrates this. By embedding sustained PPIE throughout its work – including this blog written by a patient advocate – it has built trust and support for data use, even with an opt-out model. The approach offers a scalable model aligned with NHS values and public expectations.

This is **how** Flatiron Health UK achieved it

Trust is the foundation

Trust is central to any data initiative. People must feel confident their data is used ethically, securely and in line with their values – but this trust is fragile.

When decisions happen behind closed doors – especially with private companies – distrust flourishes. Early and consistent involvement builds collaboration, fosters a sense of ownership, and ensures decisions reflect real-world needs.

Flatiron Health UK believes that PPIE must be central to any health data initiative.

Enabling choice

In its first local partnership Flatiron Health UK consulted widely with patients, local communities and the Leeds Teaching Hospitals NHS Trust on how best to offer patients a choice in whether their health data is used for research.

The resulting opt-out process aims to reach everyone to give them the opportunity to opt-out of their health data being curated, anonymised and shared for cancer research and improved patient care.

Flatiron Health UK was committed to dedicating the resources needed to carry out the opt-out process, at no cost to the NHS.

This included:

- Funding and training staff to run the opt-out process.
- Running an opt-out helpline and email host to answer questions, share information and action opt-outs.
- Co-creating core information materials with patients and communities, including the main letter to patients.
- Sending out more than 38,000 letters by April 2025, aiming to ultimately reach every cancer patient eligible to be included.
- Ensuring that patients who choose to opt-out are excluded from datasets (this includes those who have already opted out through the National Data Opt-Out).

By the end of April 2025, more than 38,000 letters had been sent to patients eligible for inclusion. Around 4% of people choose to opt-out from sharing their data with Flatiron.

Learnings to date from the opt-out model in Leeds include:

- Involve local communities, patients and staff in consulting on the opt-out model, and how it will work.
- Invest significant resource in giving patients a choice about whether their data is used for purposes beyond their individual care and treatment, making it easy for people to find more information in the way right for them, whether by letter, email or phone.

Better outcomes through unique insights and experience

PPIE isn't just about optics. It tangibly improves outcomes.

Public and patient voices offer insights often missed by data scientists, policymakers and business leaders, helping to shape better questions, identify key risks, and highlight what truly matters.

To be meaningful, findings must resonate with people living with cancer. More detailed, disaggregated data helps local teams improve care and gives patients relevant engaging information.

Flatiron Health’s mission is to improve and extend lives by learning from the experience of every person with cancer.

Accountability and power balance

Public-private data relationships often carry power imbalances. Without meaningful patient involvement, commercial interests can shape data use to benefit the few.

Embedding PPIE helps rebalance these dynamics, creating accountability and ensuring data-driven innovation serves the public good. This doesn’t mean stifling business – it’s about sharing value, and ensuring equitable benefits.

Flatiron Health UK has an established Patient Voices Panel which directly informs its UK business strategy and operations and consults an independent Research Transparency Panel to oversee data use. This panel includes patient and lay representatives.

Transparency begins with inclusion

A major criticism of public-private data sharing is a lack of transparency. Healthcare data decisions can feel opaque, or overly technical to the average person.

PPIE counters this by making the process more human and accessible. It clarifies trade-offs, communicates intentions clearly, and fosters a culture of openness.

National patient advocacy is fundamental to Flatiron Health UK. It engages with patient organisations and the wider public using online and offline channels such as conferences, webinars, blogs, roundtables and video explainers.

Leading, not lagging

PPIE is too often an afterthought. To be effective, it must be the starting point – in agenda setting, design, governance and evaluation. It must also reflect regional diversity and equity. Living with cancer in London is very different from living with cancer in the Outer Hebrides.

Flatiron Health embraces the joy of local. With each of its NHS partners, it co-designs and delivers tailored PPIE programmes to explain how and why patient data will be used, and gathers data using workshops, surveys, focus groups, posters, leaflets and letters.

Working together to prioritise the patient and public voice

Developing an effective PPIE strategy takes time and commitment from all partners. From the start of the journey, more than three years before launch, Flatiron Health UK worked extensively with Leeds Teaching Hospitals NHS Trust (LTHT) to engage patients, the local community and staff members.

Patients help define the strategy

The Patient and Public Engagement Programme was co-designed by Flatiron with patients and the Trust's PPIE team. It followed 4 steps:

1. Raising awareness
    - A multi-media campaign about the potential partnership, including using posters and TV monitors across the Trust to reach "ordinary patients".
2. Creating accessible materials
    - Including information leaflets, infographics, worksheets and easy-read versions reviewed by the Leeds Learning Disability People's Parliament.
3. Holding focus and listening groups
    - Reaching out to the local community to help them better understand the request for their involvement and gather their feedback.
4. Surveying views
    - Including sending surveys to around 2000 people in the local community, and seeking views face to face and electronically, capturing insights on the proposed partnership and an opt-out model.

Learnings from the ongoing programme include:

- Engagement of patients and the public is a critical part in the establishment of a private-public partnership, providing a stronger footing for collective ownership.
- A comprehensive PPIE strategy needs to be created by working together to ensure inclusive, ongoing engagement of local and wider communities across the UK.

Partnership with patients turns data into meaningful change.